

OUR FAMILY PICTURE

Welcome to First Steps!!! This workbook was created by family members of children already involved in First Steps services, to help families beginning services. We hope you will complete the workbook, keep it updated, and please...take time to enjoy the journey. You'll be glad you did.

We want to help you look at your family, your schedule and your wants and needs. As your family begins First Steps services you will join a new team built around you and your child's needs. The workbook is designed to help you choose a team of people who will best fit you and your family's lifestyle. You are a key member of the team that will work together to plan services for your child and family. We also hope the workbook will help you to understand your roles and responsibilities in these decisions.



My Family/Child

Please note: There may be parts of the workbook you do not complete. You may want to keep it in a special place where you can return to it often to update your schedule, your family's needs or to choose new team members. You may also want to paste a picture of your family or child in the above space.

OUR FAMILY PICTURE

To begin making decisions about your family's needs, list your family members and activities. This information will help your planning team know your family better and help them guide you in deciding what services best fit your needs. Please take some time to fill out this family picture to share with your service providers.

Address _____ Home phone number _____
City/State _____ Zip _____

Adults in House

<u>Name</u>	<u>Age</u>	<u>Work hours</u>	<u>Work phone</u>	<u>Special needs or concerns</u>
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

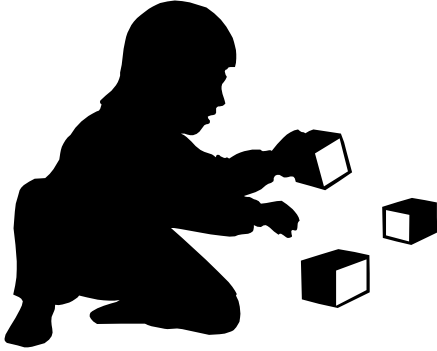
Children in House

<u>Name</u>	<u>Age</u>	<u>School/Work hours</u>	<u>School/Work phone</u>	<u>Special needs or concerns</u>
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

Others Living in House

<u>Name</u>	<u>Age</u>	<u>Work hours</u>	<u>Work phone</u>	<u>Special needs or concerns</u>
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

OUR FAMILY PICTURE



Cultural Information

Please feel free to list any information which may influence your choice of team members. Some ideas are provided for you as well as blank space for your special concerns.

Race/Ethnicity:

Languages spoken:

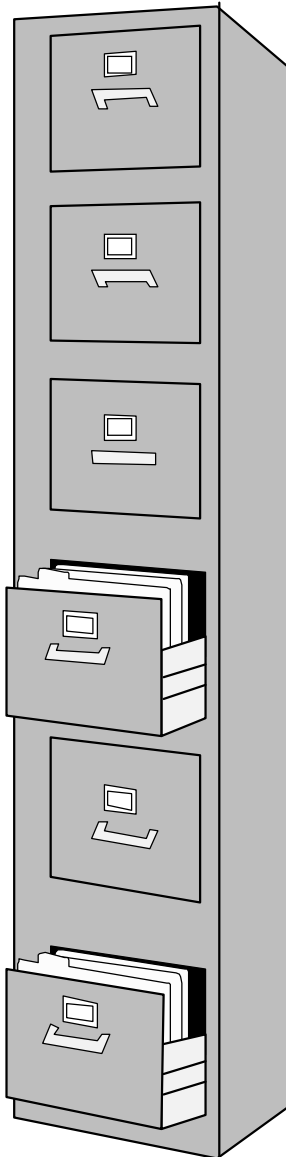
Religion(s):

Other cultural or religious beliefs affecting provision of First Steps services or choice of provider:

OUR FAMILY PICTURE

Medical Coverage

Please take time to gather the following information now. It will be needed by many of your team members in the future. It would also be helpful to bring any insurance or Medicaid cards to your First Steps meeting.



Insurance Company _____
Policy Number _____
Phone Number _____
Insured's Name _____

Insurance Company _____
Policy Number _____
Phone Number _____
Insured's Name _____

Insurance Company _____
Policy Number _____
Phone Number _____
Insured's Name _____

Medicaid Information: (List the names and Medicaid numbers of your children receiving services.)

Name _____

Medicaid Number _____

Name _____

Medicaid Number _____

Name _____

Medicaid Number _____

Name _____

Medicaid Number _____

Do you receive benefits from the Children with Special Health Care Needs program?

Yes _____ No _____

"I think any time a child leaves the hospital with any kind of problem, the hospital should give the parents a file cabinet to keep track of all his records"

- Children with Cerebral Palsy - A Parents' Guide
ed. Elaine Geralis

OUR FAMILY PICTURE

About our Family

List things your family likes to do together:

List people who are important to your family (Relatives, neighbors, friends or church members):

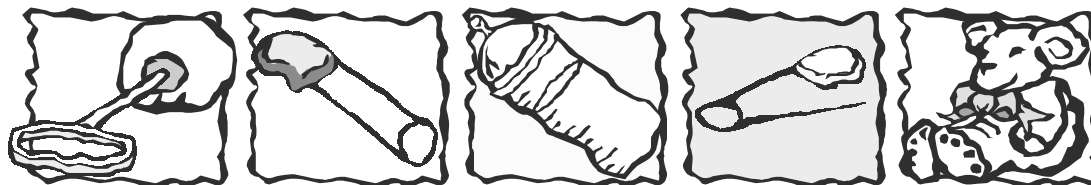
Are there planned activities throughout the year your family attends? Please list them.

List people involved in the care of your children: (grandparents, baby-sitters, nursery or daycare workers)

"Kyle's grandparents on both sides have been wonderful from the start. They're always asking us what they can do to help out with Kyle.

- Children with Cerebral Palsy - A Parents' Guide

ed. Elaine Geralis



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Our Family Schedule

The next step to making decisions about your family's needs is to use the people and activities you listed in your "family picture" to help you decide when and where services best fit in your schedule. Look at each family member's work or school schedules and activities and fill in the following calendar of monthly activities.

Suggestions for completing your monthly calendar:



Include the following:

- Work schedules of family members.
- Scheduled activities of children including school, sports, music or dance lessons and other activities.
- Regularly scheduled appointments
- Schedule for church, clubs, organizations, committees and other social events.
- **Remember to block out personal time.**

Feel free to copy the following pages of this calendar or find one that fits your family's needs!

"We decided that any child would have to fit into our lives. For example, Laurie has so many appointments and needs, but I had originally decided to go back to work. I adjusted and went back part time. I decided I needed that for myself. We still had to go out at night. We still had to have time alone."

Babies with Down Syndrome - A New Parents Guide

ed. Karen Stray-Gundersen

"I do his exercises two times a day with stretching and his physical and occupational therapy as instructed. He can get a breathing treatment every four to six hours and he gets four feedings a day, every four hours. I just live by the clock." ~ an Indiana family member

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Our Family Schedule

**"We have become very good at writing things down as they come up so that we can go prepared to our appointments."
~ an Indiana family member**

Month _____
Year _____



Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

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Thinking About Your Needs

Before choosing service providers, think about what is important to your family. The following is a list of questions developed by other families which you may find helpful. Consider what you need for yourself, your child and your family and what you want from a provider. The questions listed may suggest other questions you want to ask. Take your list to your meeting with your service coordinator to help you when selecting a provider.

Thinking through my family's wants and needs:

- ⇒ What does my family do or enjoy that we want to continue after beginning First Steps?
- ⇒ What, if anything, are we willing to give up to fit services into our family life?
- ⇒ What plans do we have for the next 6 months? one year? five years?
- ⇒ What things are important for our child in the next 6 months? one year? five years?
- ⇒ What concerns do we have about receiving First Steps services?
- ⇒ How do we want to be involved in our child's First Steps services?
- ⇒ How does our family react to challenges?
- ⇒ What strengths do we bring to new situations? How are decisions made in our family?
- ⇒ Who can we depend on for support (friends, family, church members)?

“Last year, after he was born, one of our friends organized all our other friends to cook meals for us all summer. That was incredible!”
~an Indiana family member

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“The person who probably helped me the most throughout this past year was his case coordinator. She seemed to have a pretty broad grasp of what’s out there, what’s available. She would bend over backwards, and was willing to give me information about other options” ~ an Indiana family member

Thinking through what we need from a team member:

- Do we prefer a new graduate who may have new ideas or someone with years of experience who may use one or two strategies which work for them?
- Do we prefer someone who has practical experience with children 0 to 3 years?
- When will services best fit into our schedule? How and where will services best fit our needs?
- Do we want a provider to give us activities to follow through with therapy at home? Do we want to learn how to work with our child at home?
- Do we feel it is important to have someone who is the same race as ourselves or our child? the same gender as our child? the family member of someone with special needs?
- Do we prefer someone business like or who feels more like family?

OUR FAMILY PICTURE

Questions to ask Providers

Before you choose a service provider, it is important to talk with providers who can be there when and where you need them. Your planning team can give you names and telephone numbers of providers who meet your needs. You should feel free to call and speak to as many as you wish before making a decision. You may want to look at the following questions and mark those which are important to you before calling a provider.

Provider Profile

- What is your educational background?
- What experience do you have with children age 0 to 3?
- Why did you choose your job?
- Are you a family member of a person with special needs?
- Are you a member of a professional organization?

Philosophy

- How do you involve families in services?
- How do you deal with conflict if we don't agree?
- How do you work with a crying child?
- Will you teach us to work with our child between visits?
- Will you teach other caregivers such as grandparents or daycare providers?
- Will you give us a plan to follow at home?
- How do you share information with family members and service providers?
- What techniques do you use during your visits?
- What equipment do you use during your visits?

OUR FAMILY PICTURE

Special Criteria

- What hours and days are you available?
- Do you have an opening to take our child now?
- How flexible are you with schedules?
(Can you come at 9:00 a.m. this week and 10:00 a.m. next?)
- Are you available between visits if we have concerns or questions?
- Do you work in homes, preschools, or other places our child may be?
(Will you come to my child's grandparents' home for visits?)
- Do you provide individual services? group services?
- With the family's permission, can we talk to other families with whom you have worked?
- Can we watch you work with another child (with the permission of the parents)?
- Have you ever worked with our child's disability or something similar?
- Are you enrolled as a First Steps provider?
- If not, how will your fees be handled?
- Can services be coordinated? How?
(Can we have physical and occupational therapy at the same time?)
- Are you able to help us select equipment and materials if needed
(wheelchairs, communication boards, etc.)?

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Connecting with Others

Sometimes it helps to just know you are not alone. Often other families can share ideas which can help you better meet your child's needs. Families may share a helpful hint which makes daily life easier for you and your child. They may also have information about special doctors, medical procedures or equipment to benefit your child. Many families find it helpful to talk to other families who have children with similar needs. Family to family contact can also lead to life long friendships.

There are several ways you might find other families with whom you can talk. Ask a member of your planning team if they know of a parent group you could contact. Also ask if they know of a parent whose child has needs similar to your child's needs who might be willing to talk. Let your planning and service teams know it is okay to give your name and telephone number to parents who want to connect with other families. Service providers like doctors, therapists and social workers may also be able to connect you with families.

You may want to contact local or national advocacy groups who can share information with you. Please see the list at the end of this book for names and telephone numbers of some organizations. Many groups also have websites.



"To people who live with exceptional children, the problems associated with just getting through one more day can be overwhelming. We have all the problems and obligations that ordinary families have, PLUS. Our situation is, at the very least, different. Talking to other people who have had days much like your own provides an emotional outlet that, at least in my experience cannot be found anywhere else."

*- Acceptance is Only the First Battle
Jan Mariska*

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A Final Word

We hope working through this Family Picture has helped you to make some decisions about what is best for your family. Many times the demands of daily life are greater than the time families have to deal with them. It is important to define your family's priorities and then decide how the new needs of your child fit into the rest of your family's lifestyle.

Sometimes it's hard to accept that we cannot do everything we feel we should for our children. However, if we as parents know that we have put much thought into setting our priorities, it is easier to accept the compromises we must make. In the end, we need to feel good about our choices and accept the journey we have begun.

"We need respect, we need to have our contribution valued. We need to participate, not merely be involved. It is, after all, the parent who knew the child first and who knows the child best. Our relationship with our sons and daughters is personal and spans a lifetime."

- Working with Professionals
Cory Moore, mom, NICHCY

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Northern Indiana:

Agape Respite Care
415 West Franklin Street
Berne, IN 46711
219-589-3351
219-589-2846 (fax)

Family Resource Center of
St. Joseph County
809 North Michigan St.
South Bend, IN 46601
219-284-7157

First Directions
McAllister Center
2351 North 20th Street. Room 8
Lafayette, IN 47904
765-423-1460

Central Indiana

First Steps for Families
500 East Eighth Avenue
Terre Haute, IN 47804
812-231-8342
812-231-8208 (fax)
Email: FamNetwork@aol.com

Indiana Easter Seals Society
3816 E. 96th Street
Indianapolis, IN 46204
317-844-7919

MEPHIBOSHETH Resource Center
(dispeller of Shame)
Franka York
P.O. Box 174
New Ross, IN 47968
765-723-1721

Resources



OUR FAMILY PICTURE

Resources

Southern Indiana

Assistive Technology Training and
Information (ATTIC)
3354 Pinehill Drive
Vincennes, IN 47591
812-886-0575
812-885-1128 (fax)

PATH Partners Acting Together
Old Court House Center- Suite 101
201 Northwest 4th Street
Evansville, IN 47708
812-424-8600
812-424-8603 (fax)



State Wide

Governor's Planning Council for
People with Disabilities
143 West Market St.
Suite 404
Indianapolis, IN 46204
317-232-7770

The Arc of Indiana
22 East Washington Street
Suite 210
Indianapolis, IN 46204
317-257-8683/ 317-251-7488 (fax)

Indiana Parent Information Network
(IPIN)
4755 Kingsway Drive Suite 105
Indianapolis, IN 46205
317-257-8683 or 1(800)-964-IPIN
317-251-7488 (fax)

First Steps Early Intervention System
Bureau of Child Development
402 West Washington Street
Room W 386
Indianapolis, IN 46204-2739
800-441-STEP (7837)
317-232-1144/ 317-232-7948 fax

IN*SOURCE

Indiana Resource Center For
Families with Special Needs
809 North Michigan Street
South Bend, IN 46607-1036
800-332-4433 (219) 234-7101
219-234-7279 (fax)

Indiana Brothers and Sisters
Network (siblings group)
4755 Kingsway Drive Suite 105
Indianapolis, IN 46205
317-257-8683

OUR FAMILY PICTURE

National Groups:

National Information Center on
Children and Youth with Disabilities
(NICHCY)

P.O. Box 1492
Washington, D.C. 20013-1492
1-800-695-0285
202-884-8441 (fax)

National Organization for Rare
Disorders (NORD)
P.O. Box 8923
New Fairfield, CT 06812-8923
1-800-999-6673
203-746-6481 (fax)

National Parent to Parent Support
and Information System
P.O. Box 907
Blue Ridge, GA 30513
1-800-651-1151
706-632-8830 (fax)

Sibling Information Network
AJ Pappanikou Center
62 Washington Street
Middletown, CT 06475
203-344-7500

Family Voices
PO Box 769
Algodones, New Mexico 87001
505-867-2368

Mothers for Moral Support (MUMS)
c/o Julie Gordon
150 Custer Court
Green Bay, WI 54301-1243
414-336-5333

Websites:

Family Education Network
<http://www.familyeducation.com>

Indiana Parent Information Network
Indiana's Central Directory
<http://www.ai.org/ipin>

National Parent Network on
Disability
<http://www.npnd.org>

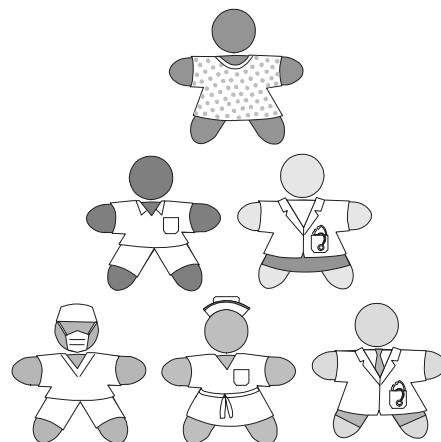
The ARC of the United States
<http://thearc.org/welcome/html>

National Information Center for
Children and Youth with Disabilities
<http://nichcy.org>

Family Village
<http://www.familyvillage.wisc.edu>

Zero to Three
National Center for Infants and
Toddlers
<http://www.zerotothree.org>

ComeUnity: Family Support For
Adoption and Disabilities
<http://www.comeunity.com>



OUR FAMILY PICTURE

This Workbook was created by the
1998 Family Perspectives
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